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PRINCIPAL INVESTIGATOR: Andrea F. Patenaude, Ph.D.

CONTRACTING ORGANIZATION: Dana-Farber Cancer Institute
Boston, MA 02215

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Andrea F. Patenaude, Ph.D.

E-Mail: andrea_patenaude@dfci.harvard.edu

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14. ABSTRACT

The goals of this study are to 1.) Describe in-depth the knowledge, attitudes, health behaviors, and life plans of a cohort of 40 daughters, ages 18-24 years, of mothers who are BRCA1/2 mutation carriers, and 2.) Define specific health educational, psychological, insurance and medical needs of this population. The major data source for this project are the 40 in-depth, qualitative (semi-structured), telephone interviews with 18-24 year old daughters of BRCA1/2 mutation carriers . Preliminary analysis suggests that there are significant gaps in essential breast cancer genetics knowledge among this cohort, supporting the need for a targeted educational intervention. We have now completed our work with the Dana-Farber/Harvard Communications Core, graphic designers and cancer communication experts, to design the small pilot version of the intervention. We have very recently received approval from the USAMRMC IRB and are ready to begin recruitment of eligible daughters for pilot testing of the intervention materials. A manuscript reporting on the reactions, distress and genetic testing plans of this at-risk population is also in progress.

15. SUBJECT TERMS
Genetic Testing, breast cancer, prevention, BRCA1/2, education

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Table of Contents

INTRODUCTION: Data from this study has the potential to answer an important question about genetic testing, i.e. what do those who are told by a relative, especially those informed as children, understand about hereditary breast cancer and what are the gaps or misperceptions in their knowledge? Are the gaps sufficient to cause us to challenge the present mode of spreading family information about hereditary risk by word of mouth through relatives? Are there ethical, more flexible models professionals might adopt? We know that not all relatives are informed and that while much telling occurs soon after testing, in some cases, it is delayed many years. We know that parents who are mutation carriers worry most about impact on their children, yet we know little or nothing about what those children understand. We believe that an educational intervention to help inform young women as they come to an age at which they can make independent decisions about genetic testing would be valuable and potentially life-saving in its impact, encouraging them to seek genetic counseling and testing and to consider earlier and with more accurate information, the choices they face with regard to their hereditary cancer risk. The goals of this study are 1.) Describe in-depth the knowledge, attitudes, health behaviors, and life plans of a cohort of 40 daughters, ages 18-24 years, of mothers who are *BRCA1/2* mutation carriers, and 2.) Define specific health educational, psychological, insurance and medical needs of this population. Having this data has enabled us to proceed towards development of a health educational intervention targeted to the identified needs of 18-24-year-old daughters of *BRCA1/2* mutation carriers, which will ultimately reduce mortality and morbidity. The major data source for this project are the 40 in-depth, qualitative (semi-structured), telephone interviews with 18-24 year old daughters of *BRCA1/2* mutation carriers. Additional quantitative data has been gathered from subjects including demographic and family history questions, the Brief Symptom Inventory-18, Impact of Event Scale and the Breast Cancer Genetic Testing Knowledge Scale. Subjects were selected for maximal diversity (family history, socio-economic status, cultural differences), from among the age-eligible daughters of the approximately 1000 *BRCA1/2*-positive women who have been tested at the DFCI, the Mass General Hospital (MGH), and the Beth Israel Deaconess Medical Center (BIDMC) between years 2000-2009.

BODY: We have completed the recruitment and enrollment of 40 daughters of *BRCA1/2* mutation carriers, ages 18-24. These 40 participants have completed both the quantitative assessment and qualitative interview components of our study. This represents major progress in Year 2, after an initial year in which progress was limited due to IRB and access issues. It should be noted that the accessing and enrolling of these 40 daughters of *BRCA1/2*-positive mothers required a good deal of effort. One hundred and one mothers with one or more age-eligible daughters who had received genetic counseling and testing at one of three Harvard teaching hospitals were approached. Our pool was reduced to 80 mothers with potentially eligible daughters since 21 mothers were either found to be ineligible, were not able to be reached or had died. A total of 22 mothers declined to provide their daughter's contact information and an additional five mothers were unresponsive to multiple attempts to contact and are considered passive refusers. Fifty-three mothers (66%) provided contact information for their daughters. We invited 58 daughters to participate in our study (more than one daughter was recruited in five families when daughter #1 was either unresponsive to multiple attempts to contact (3) or had served as a pilot subject (2)). One daughter whose mother had very recently died became ineligible during the course of our inquiry. Two daughters actively declined and nine were not responsive to multiple contacts and were assumed to be passive decliners. Forty-

four daughters agreed to participate (5 pilot and 40 research subjects) and have enrolled completed both the quantitative and qualitative portions of the study for a participation rate of 78%. One additional daughter was consented and completed the quantitative assessment for our study but became unresponsive to attempts to contact for the purpose of scheduling her qualitative interview. This daughter's quantitative data will not be used in the data analysis phase of our study. The development of the coding book for the study was completed by the end of Month 28. All of the qualitative interviews have been transcribed and coded. Reliability scores over 80% were achieved among 3 trained coders.

Findings to date from our study are that daughters of mutation carriers remember learning that their mother is a *BRCA1/2* mutation carrier and also remember advice from the disclosing parent about how they should utilize this information. Knowledge of mother's mutation status was not associated with higher-than-average general distress (as measured by the BSI-18), which may encourage parental disclosure in the future. Daughters did report considerable cancer-related distress (as measured by the IES and self-report). About a quarter of the daughters had scores on the IES above the level of the clinical cutoff and about a third reported ratings of "very high " or "to an extreme" on a 5-point Likert scale of cancer related distress. Daughters also had considerable misconceptions in their thinking about hereditary cancer risk and genetic testing. They reported high anxiety about the potential impact of their hereditary cancer risk and desire to undergo risk-reducing surgery on their childbearing plans. They worried about the health of their largely unborn children. While most plan to undertake genetic testing (and 7 of the 40 had already had testing), some ambivalence or hesitancy about the timing of testing was evidenced, with daughters citing a wide range of possible times when they might seek testing. Some feared that identification as a mutation carrier could have adverse emotional effects, while others cited beliefs about the inevitability of their getting cancer to explain why they were not worried about the outcome of genetic testing. Various trajectories of cancer worry were reported, with diminishing anxiety cited by some daughters over time as they adjusted to knowing their mother's mutation status. Others reported increasing cancer-related anxiety as they got older and closer to the time when they should begin testing or screening or when cancer might be more likely to occur.

PRESENTATIONS:

In April 2011, preliminary data from the study was presented in plenary session at the International Meeting of Psychosocial Aspects of Hereditary Cancer in Amsterdam, the Netherlands. In addition, an abstract was accepted for poster presentation at the 2011 DOD Era of Hope conference in Orlando FL. The data reported showed that young, high-risk women have inadequate knowledge about their cancer risks and about the options for detecting or preventing the cancers for which their risks are remarkably increased. Educational interventions may reduce their anxiety about hereditary breast or ovarian cancer and ultimately improve their participation in effective screening and risk-reducing interventions that improve survival and quality of life. Our project was selected at the Era of Hope meeting for participation in the meeting press conference and in the 2012 CDMRP Breast Cancer Research Program announcement. Both of the abstracts have been included in the appendix of this annual review.

No Cost Extension: In January 2012 we requested a 12-month No-Cost Extension of this project due to long (5 months total) delays in IRB approval of our Phase 2 amendment. On January 18, 2012 the request for the 12-month NCE was granted.

COMPLETED TASKS:

Develop Interviews: Months 0 to 4
Develop questionnaire: Months 0 to 4
Get approval from DFCI/HCC and USAMRMC Institutional Review Boards: Months 2-8
Consult with and review materials with consultants: Months 1-7
Pilot Interviews and questionnaire: Months 13-14

Contact mothers for permission to contact their daughters, accrue and consent Patients: Months 12-20 – We wrote to 101 mothers who are *BRCA1/2* mutation positive and who we believed had daughters 18-24 years of age requesting contact information for their daughter. Five mothers, we learned, were deceased. In eight cases, we did not have accurate or updated contact information for the mother. Eight mothers were ineligible (four did not have a child in our identified age range, five had not yet told their daughter about their test results, and one had a daughter with special needs whom the mother didn't feel would be able to complete the requirements for the study on her own). The percentage of eligible mothers who provided contact information for one or more age-eligible daughters was 66%.

Train research associate for interviewing: Months 14-15 – We trained a total of four graduate student research interviewers. Three were originally trained, but one had to drop out after doing four interviews because of the burden of her graduate studies. A second interviewer also had serious medical problems which interfered with her being able to complete the last several interviews assigned to her. All interviewers had prior academic coursework on qualitative interviewing and had conducted research using qualitative methods. Each interviewer read the study protocol and discussed the project aims with Dr. Patenaude. Questions were answered regarding the nature of the study population, *BRCA1/2* genetic testing and screening and surveillance recommendations for mutation carriers, the extent of probing demanded by the interview schedule, respect for autonomy of subjects and their rights to not answer or to discontinue the interview. Interviewers were trained in persistence and call strategies necessary to reach and schedule the interviewees and were provided with information about preferred times for contact for each subject. They were also extensively trained in the handling of any subject distress which might arise and had 24-hour contact information for the PI and project RA (both mental health professionals), both of whom were informed of when interviews were being conducted.

Monitor interview quality and consistency: Months 16-22 - All interviewers read two transcripts of Dr. Patenaude, the PI, conducting project pilot interviews. The first three interviewers conducted a pilot interview which was listened to with the PI at length for suggestions about improvements in the approach to questions and handling of follow-up questions. By the time the last interviewer joined the project, all pilot interviews had been conducted, so she could not do a pilot interview. She was a highly experienced interviewer, however, and she listened to the tape of Dr. Patenaude conducting a project pilot interview and

went over it in detail with Dr. Patenaude before conducting her own first interview on this project. All first interviews were listened to together by Dr. Patenaude and the interviewer for suggestions about improvement. As needed, additional interviews were listened to with Dr. Patenaude until it was felt that interviewer quality was established.

Conduct interviews: Months 16-26 – Forty subject interviews which averaged 56 minutes in length were conducted via telephone. These interviews required an average of five phone calls each to schedule with this highly mobile, busy group of young adults. The interviews were all conducted in one session. One subject reported minor distress, but, when followed up with a phone call from the PI, the subject said she was fine and no further distress was noted by the PI. Many subjects found the interview helpful and/or interesting. All subjects who initiated an interview completed the interview and no topics were omitted.

Developed database and entered quantitative data: Months 12-26 – Quantitative responses of all 40 subjects who completed participation in the project have been entered into the project database. Statistical analyses have been conducted by the project biostatistician, Dr. Julie Aldridge, of the Dana-Farber Department of Biostatistics and further analyses on data to be published in the first project reports are underway.

Transcribe interviews: Months 16-27 Interviews were transcribed by Cambridge Transcriptions, an experienced transcription company which does local court recordings and transcribes for other major research universities in the Boston area. In addition, they provided us with digital records of the interviews. The project RA, listened to the digital recording to insert or correct any missing or incorrectly transcribed material. This should guarantee that the transcription is a highly accurate record of the conversation which took place during the telephone interview.

Develop coding manual: Months 24-28– Using Atlas-ti, a coding manual was developed. The PI coded a number of pilot and project interviews, creating and editing the code book as she proceeded. These codes were discussed with the research team to ensure that they allowed us to answer all of the questions we proposed to answer with this research. We then honed down the final Code Book which was used to train the other coders. The project interviews which were used to develop the Code Book were recoded along with the remaining interviews.

Hire and train coders: Months 25-29 – We utilized currently employed staff to code the interviews. Training involved reviewing of the codes with Dr. Patenaude to make sure there was a shared understanding of their meaning and limits. Coders then coded 1-2 training interviews from the group of pilot interviews. These were reviewed and discussed with the interviewers. Coding of the first several project interviews were also discussed with Dr. Patenaude to ensure the reliability and consistency of the application of codes.

Coding of interviews: Months 27-31 – The coding is completed for all 40 subjects. Reliability of over 80% was established between coders.

Worked with consultants to develop the psycho-educational intervention: Months 25-32 – We discussed our study findings and plans for the development of the educational intervention

with Drs. Tung, Ryan, Garber, Partridge and Tercyak. We enlisted their suggestions for the nature and format of the intervention that we developed. We have now completed our work with Catherine Coleman and the Dana-Farber/Harvard Health Communications Core, graphic designers and cancer communication experts, to design the pilot pages of the intervention which we will present to 10 subjects for feedback to help in design of the ultimate intervention. We have completed discussion of the overall outline of the intervention and the parts which are developed now. The home page of the intervention and a section landing page ("Genetic Counseling") and an inner page of another section on "Dating and Hereditary Cancer" have now been completed. The graphics for these sections have also been completed and are included in page 40-45 of the appendices. We were very pleased with the graphic design for the web pages and with the presentation of content on these pages. Two graphic versions of the home page were completed so that they can be compared in the pilot test with daughters of mutation carriers. We have also completed formulation of the questions to be asked of participants in the piloting (pages 36-41 of the appendices). These materials were submitted to the DFCI IRB and we received approval on 11/23/2011. On 12/2/2011 we submitted an amendment for the pilot intervention to the USAMRMC IRB. We received approval on 3/7/2012 and we are now beginning the recruitment of eligible daughters for pilot testing of the intervention materials.

Pilot educational intervention: Months 37-41 – We have assembled the names and addresses of the mothers we need to ask for daughter's contact information; the daughters are potential subjects for part 2 of our research project, the piloting of our mini-intervention. USAMRMC IRB approval has been received and we will begin contacting these mothers and daughters. We have been in touch with the site PIs at the collaborating hospitals to request review of the status of the mothers whose daughters we plan to contact to insure that there have been no maternal deaths in the interim. A staff research assistant has been trained to conduct the telephone interviews for the pilot intervention. She has worked extensively over several months on her interviewing skills under the direction of Dr. Patenaude. She has also conducted and recorded several practice telephone interviews on volunteers. Dr. Patenaude has reviewed these recordings and feels that the RA is well prepared to conduct the 10 study interviews for the pilot testing of the intervention materials.

Analyze coded data: Months 17-26: Revised expected period: Months 27-46

Integrate qualitative and quantitative data: Months 24-28: Revised expected period: Months 29-47.

Write journal articles, research reports, parent brochure or web content: Months 25-48
We are in the process of writing the first of our anticipated publications from this project, a journal article for submission to a major research journal which will report on the daughters' memories of parental disclosure and advice regarding hereditary cancer risk, their knowledge and misconceptions about *BRCA1/2* inheritance, and the nature and extent of their cancer-related distress and future plans for genetic counseling and testing. This will be a mixed methods report. Future reports will focus on daughters' specific knowledge of and plans for breast cancer screening and risk reduction, desires for related psycho educational materials and preferred information formats. Writing for publication will continue through the end of the project.

Plan further research: Months 34-48 – We will be seeking additional funding for gathering similar data from daughters whose mothers have died from breast cancer and from daughters of fathers who are mutation carriers. We also seek major funding for further development and testing of our breast cancer genetics educational intervention for young adult daughters of women who carry *BRCA1/2* mutations. We also hope to be able to conduct similar assessments of two additional groups of daughters of mutation carriers, daughters of fathers who are carriers and daughters of deceased mutation carriers.

KEY RESEARCH ACCOMPLISHMENTS:

- Established the feasibility of accessing young adult daughters of living *BRCA1/2* mutation carriers using our method of contacting them by accessing their contact information from their mothers. Compliance rate for mothers: 66%
- Conducted 40 interviews with 18-24 year old daughters of mothers who are *BRCA1/2* mutation carriers. Established the feasibility of reaching and enrolling young adult daughters of *BRCA1/2* mutation carriers in psychosocial research. Compliance rate: 78%
- Completed assessment of breast cancer genetics knowledge, emotional distress and cancer-related distress among 40 daughters of *BRCA1/2* mutation carriers.
- Scored and entered research data on quantitative assessments for 40 daughters of mutation carriers.
- Transcribed and coded all 40 interviews
- Designed the pilot pages of the intervention and have received DFCI IRB approval and USAMRMC approval for Phase 2 of the project.

REPORTABLE OUTCOMES:

1. Patenaude, A.F., Tung, N., Ryan, P., Hewitt, L., Garber, J.E. (April, 2011). *What Do Young Adult Daughters of BRCA1/2+ Mothers Know about Hereditary Risk; How Much Do They Worry?*; Presented at the 12th International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC), Amsterdam, The Netherlands.

2. Patenaude, A.F., Tung, N., Ryan, P., Hewitt, L., Garber, J.E. (August, 2011). *What Do Young Adult Daughters of BRCA Mutation Carriers Know about Hereditary Risk and How Much Do They Worry;* Presented at The Department of Defense (DOD) Breast Cancer Research Program 6th Era of Hope Conference, Orlando, Florida.

3. Applied for Department of Defense Clinical Translational Award, September 2011.

4. Applied for DF/HCC Men's Collaborative to Cure Women's Cancer Award, November 2011.

CONCLUSION:

We have established the feasibility of reaching out to mothers who are in the *BRCA1/2* cancer registries at three teaching hospitals and, through contact information they provided, of accessing and enrolling young adult daughters of *BRCA1/2* mutation carriers for psychosocial studies in hereditary cancer. This study is yielding quantitative and qualitative measures of the young women's knowledge of breast cancer genetic testing and of their own hereditary cancer risks, their attitudes towards information acquisition about hereditary breast cancer and *BRCA1/2* genetic testing, and their knowledge of and plans to utilize (or not utilize) recommended screening strategies or risk-reduction options. Preliminary analyses suggest that there are significant gaps in essential breast cancer genetics knowledge among this cohort. Data also show that there is high cancer-related distress among 18-24 year old daughters of mutation carriers, especially related to their mother's and their own cancer risks and childbearing plans. Our data strongly suggests that young adult daughters of mutation carriers are a population of high-risk women who have, to date, been neglected in terms of provision of genetic services, Psycho-educational interventions aimed at this population should be developed to improve genetic knowledge and reduce cancer-related distress.

REFERENCES:

Derogatis LR (2000). Brief Symptom Inventory 18: Administration, Scoring and Procedures Manual (3rd Ed.). Minneapolis: National Computer Systems.

Erblich J, Brown K, Kim Y, et al. (2005). Development and validation of a breast cancer genetic counseling knowledge questionnaire. Patient Education and Counseling 56, 182-191

Horowitz M.J., Wilner N.R. & Alvarez W. (1979). Impact of Event Scale: A measure of subjective stress. Psychosom Med 41, 209-218.

APPENDICES:

Abstract for International Meeting on Psychosocial Aspects of Hereditary Cancer (IMPAHC)

Presented at the 12th International Meeting on Psychosocial Aspects of Hereditary Cancer, Amsterdam, The Netherlands (April, 2011).

What Do Young Adult Daughters of *BRCA1/2*+ Mothers Know about Hereditary Risk; How Much Do They Worry?

Authors: **Andrea Farkas Patenaude Ph.D.**[1]*, Nadine Tung M.D.[2], Paula Ryan M.D.[3], Larissa Hewitt M.S.W.[1], and Judy E. Garber M.D., M.P.H.[1]
Affiliations: 1: Dana-Farber Cancer Institute, Boston MA USA 2: Beth Israel-Deaconess Medical Center, Boston MA USA, 3: Massachusetts General Hospital, Boston MA USA

Introduction: Daughters of *BRCA1/2* mutation carriers have 50% chance of inheriting cancer risks up to 85% for breast cancer (often early onset) and 60% for ovarian cancer. We lack data on what young at-risk women know about their risks and recommended screening/risk-reduction measures and data on their anxiety about hereditary cancer. Data are needed for development of targeted educational materials to improve timely screening initiation and risk-reducing interventions which could reduce morbidity and, ultimately, mortality in this high- risk group.
Methods: Thirty-four daughters (aged 18-24 years) of living *BRCA1/2* -positive mothers (mothers previously tested at one of 3 Harvard hospitals) completed written questionnaires and qualitative telephone interviews about their knowledge of hereditary breast/ovarian cancer risk and screening and risk-reduction surgery, worry about hereditary cancer and the impact of their mother's genetic status on their plans for counseling/testing.
Results: Utilizing an established measure (Erblich et al., 2005), knowledge of daughters about hereditary breast cancer was significantly below that of women who had undergone genetic counseling, as shown by the absence of overlap in 95% confidence intervals of the groups. Narratives confirm knowledge is limited about screening and risk-reduction options and recommended screening initiation age. Worry about hereditary breast/ovarian cancer was high among daughters; 15% scored above the clinical cut-off of the Brief Symptom Inventory-18(BSI-18) and nearly half say they worried a great deal or to an extreme about hereditary cancer.
Conclusion: Targeted interventions are needed to educate young, high-risk women about screening and to reduce anxiety about hereditary cancer.
*Presenting author

Abstract for the Era of Hope Meeting

Presented at The Department of Defense (DOD) Breast Cancer Research Program 6th Era of Hope Conference, Orlando, Florida (August, 2011).

What Do Young Adult Daughters of *BRCA* Mutation Carriers Know about Hereditary Risk and How Much Do They Worry

Authors: **Andrea Farkas Patenaude Ph.D.**[1]*, Nadine Tung M.D.[2], Paula Ryan M.D.[3], Larissa Hewitt M.S.W.[1], and Judy E. Garber M.D., M.P.H.[1]
Affiliations: 1: Dana-Farber Cancer Institute, Boston MA USA 2: Beth Israel-Deaconess Medical Center, Boston MA USA, 3: Massachusetts General Hospital, Boston MA USA

Background and Objectives: Daughters of *BRCA1/2* mutation carriers have a 50% chance of inheriting cancer risks up to 85% for breast cancer (often early onset) and 60% for ovarian cancer. Genetic testing and uptake of enhanced screening remains sub-optimal, especially for 25-40 year old mutation carriers (Botkin, 2003; Claes 2005). Accurate knowledge is a prerequisite to informed decision making and adherence to health recommendations. We lack data on what young, at-risk women know about their risks and recommended screening/risk-reduction measures and about their anxiety related to hereditary cancer. These data are needed for development of targeted educational materials to improve timely screening initiation and risk-reducing interventions which could reduce morbidity and, ultimately, mortality in this high-risk group. A health educational intervention which provides high-risk women who are 18-24 years old with the knowledge and skills they need to adopt active coping and health-affirming screening methods at the earliest appropriate age could ultimately save lives.
The objectives of our project are to 1)Describe in-depth the genetic knowledge, attitudes, health behaviors, and life plans of 40 daughters, ages 18-24 years, of mothers who are *BRCA1/2* mutation carriers, and 2)Define specific health educational, psychological, insurance and medical needs of this population.
Methodology: Thirty-four daughters (aged 18-24 years) of living *BRCA1/2*-positive mothers (mothers previously tested at one of 3 Harvard hospitals) completed written questionnaires including the Brief Symptom Inventory-18 (BSI-18), Impact of Event Scale (hereditary cancer as the event), and Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ) and qualitative telephone interviews about their knowledge of hereditary breast/ovarian cancer risk and screening and risk-reduction surgeries, worry about hereditary cancer and the impact of their mother's genetic status on their future planning, including plans for genetic testing.
Results to Date: 38 daughters have enrolled to date and 34 have completed participation. Participation rate is 70%. Participants were an average of 21 years of age; the majority were either college students or college graduates. 88% were single. Six had mothers with no cancer history, 5 mothers had ovarian cancer, 22 had breast cancer, and one mother had had breast and ovarian cancer. Phone interviews averaged 56 minutes in length.
Knowledge of daughters about hereditary breast/ovarian cancer genetics was significantly below that of women who had undergone genetic counseling, as shown by the absence of overlap in the 95% confidence intervals of the groups' responses to a standardized instrument. Narratives confirm knowledge is limited about screening and risk-reduction options, including age at which cancer screening should be initiated. Worry about hereditary breast/ovarian cancer was high among daughters; 15% scored above the clinical cut-off of the BSI-18 and nearly half said they worried a great deal or to an extreme about hereditary cancer.
Conclusion: Young, high-risk women have little knowledge about the probabilities and options for managing the cancers for which their risks are remarkably increased. Educational interventions may reduce their anxiety about hereditary breast/ovarian cancer, and ultimately improve their participation in effective screening and risk reducing interventions that improve survival and quality of life.
*Presenting author

QUESTIONNAIRE FOR PARTICIPANTS

THANK YOU FOR PARTICIPATING IN THIS STUDY. PLEASE FILL OUT THIS FORM AND RETURN IT IN THE ENCLOSED ENVELOPE

Today's Date (please fill in): _____

Demographics

1. Date of birth: Month: _____ Day: _____ Year: 19_____

2. Current age: _____ years old

3. Gender: ☐ Male ☐ Female

4. Race: (Check all that apply)

☐ White ☐ Black or African American ☐ Asian

☐ American Indian/Alaska Native ☐ Native Hawaiian/ Pacific Islander

5. Ethnicity: ☐ Hispanic or Latino ☐ Not Hispanic or Latino

Education

6. Highest grade in school: (Check one that applies)

☐ Finished elementary or middle school

☐ High school graduate or equivalent Year graduated:_____

☐ Some college Years attended:_____

☐ College graduate -Year graduated____ Degree_____ Major:_____

☐ Post-graduate Degree: Degree _____ Field _____

☐ Other (please explain) _____

Employment

7. Occupation: _____

8. Current employment: (Check all that apply)

- ☐ Employed full time
- ☐ Employed part time
- ☐ Full time Student
- ☐ Part time Student
- ☐ Homemaker full time
- ☐ Retired
- ☐ Not employed- seeking work
- ☐ Not employed – not seeking work

Home & Family

9. Do you have sisters? (circle one) Yes No

If yes, how many?_____

If yes, how old are your sisters?_____

10. Do you have brothers? (circle one) Yes No

If yes, how many?_____

If yes, how old are your brothers?_____

11. Marital status:

- ☐ Single
- ☐ Married; Spouse's Occupation _____
- ☐ Living as Married; Partner's Occupation _____
- ☐ Separated
- ☐ Divorced
- ☐ Widow or Widower

12. If currently married: Years Since Marriage_____

13. If currently married: Spouse's **Education**

Highest grade in school: (Check one that applies)

☐ Finished elementary or middle school

☐ High school graduate or equivalent

☐ Some college

☐ College graduate

☐ Post-graduate Degree:

☐ Other (please explain) _____

14. I live most or all of the year: (Check one that applies)

☐ With parents, grandparents, brothers or sisters

☐ With wife, husband or partner

☐ In dorm, with or without a roommate

☐ With a roommate in apartment or house

☐ Alone

☐ Other_____

15. Household income:

☐ Under 20,000 per year

☐ Between 21,000 and 50,000 per year

☐ Between 51,000 and 100,000 per year

☐ Between $101,000-$149,000 per year

☐ Over $150,000 per year

☐ Don't know

☐ Don't want to say

16. Do you have children? ☐ Yes ☐ No - If no, please skip to Question **22**.

17. Number of children you have: (Please check one)

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 or more

18. Current age of daughter(s): _____

19. Current age of son(s): _____

20. Are any of these children step-children?

☐ Yes - If yes, please circle age(s) of step-child(ren) above.

☐ No

21. Are any of these children adopted?

☐ Yes - If yes, please underline age(s) of adopted child(ren) above.

☐ No

22**.** If it were up to you would you plan to have more children than you currently have sometime in your life? (please answer whether or not you currently have children)

☐ Yes

☐ No

Family History of Cancer

Please tell us about ANYONE in your family who has ANY type of cancer. We are interested in any cancer in a **blood relative**. A maternal relative is a blood relative on your mother's side of the family. A paternal relative is a blood relative on your father's side of the family.

23. Please tell us about the following blood relatives.

Relative	**Had Cancer?** (circle one)	**Type(s) of Cancer**	**Their Age at Diagnosis**	**Your Age when he/she Diagnosed**	**Is he/she currently living?** (circle one)	**If person is not living, did they die of cancer? (Circle one) (DK=Don't know)**
Mother	Yes or No				Yes or No	Yes No DK
Maternal grandmother	Yes or No				Yes or No	Yes No DK
Maternal grandfather	Yes or No				Yes or No	Yes No DK
Father	Yes or No				Yes or No	Yes No DK
Paternal grandmother	Yes or No				Yes or No	Yes No DK
Paternal grandfather	Yes or No				Yes or No	Yes No DK

24. Have any of your sisters ever had cancer? (circle one)

Yes No N/A (I don't have a sister)

For each blood-related **sister** who had cancer, list the type(s) of cancer, her age when the cancer was found, your age at that time and answer the other two questions.

Sister	**Type(s) of Cancer**	**Her Age at Diagnosis**	**Your Age when her cancer was found**	**Is she currently living?** (circle one)	**If person is not living, did they die of cancer? (Circle one) (DK=Don't know)**
1				Yes or No	Yes No DK
2				Yes or No	Yes No DK
3				Yes or No	Yes No DK
4				Yes or No	Yes No DK

25. Have any of your brothers had cancer? (circle one)

Yes No N/A (I don't have a brother)

For each blood-related **brother** who had cancer, list the type(s) of cancer, his age when the cancer was found, your age at that time and answer the other 2 questions.

Brother	**Type(s) of Cancer**	**His Age at Diagnosis**	**Your Age when his cancer was found**	**Is he/she currently living? (Circle one) (DK=Don't know**	**If person is not living, did they die of cancer? (Circle one) (DK=Don't know)**
1				Yes or No	Yes No DK
2				Yes or No	Yes No DK
3				Yes or No	Yes No DK
4				Yes or No	Yes No DK

26. Do you have any other blood relatives who have had cancer? This could include aunts (sisters of your mother or father) or uncles (brother of your mother or father) or cousins.

☐ Yes ☐ No- Skip to Question 27.

For each of your other blood relatives, who had cancer, list how he or she is related to you (your maternal aunt, paternal uncle, maternal first cousin, etc.), the type(s) of cancer, how old he/she was when the cancer was found and your age when their cancer was found.

Relation to you	**Type(s) of Cancer**	**His/Her Age at Diagnosis**	**Your Age when cancer was found**	**Is he/she currently living? (Circle one) (DK=Don't know**	**If person is not living, did they die of cancer? (Circle one) (DK=Don't know)**
1.				Yes No DK	Yes No DK
2.				Yes No DK	Yes No DK
3.				Yes No DK	Yes No DK
4.				Yes No DK	Yes No DK

Insurance

27. I have: (Check one that applies)

☐ Health insurance through my work

☐ Health insurance through my spouse's work

☐ Health insurance through my parents

☐ Health insurance from another source: _____

☐ No health insurance

28. I have:

Disability insurance	☐ Yes	☐ No	☐ Don't know
Life insurance	☐ Yes	☐ No	☐ Don't know

29. Do you think you have ever been denied or had difficulty getting any type of insurance due your family history or a known predisposition to cancer?

☐ Yes - If yes, please explain below. ☐ No

Personal Medical History

30. Do you have any significant health problems?

☐ Yes- If yes, please list below ☐ No

_____

_____

Concerns about Cancer & Heredity

31. Do you think the cancer in your family was due to an inherited predisposition to cancer in your family?

☐ Definitely not ☐ Probably not ☐ Don't know ☐ Probably ☐ Definitely was

32. How much do you worry about cancer risk being inherited in your family?

☐ Not at all ☐ A little ☐ Quite a bit ☐ A great deal ☐ To an extreme

33. How much do you worry about getting cancer in the future?

☐ Not at all ☐ A little ☐ Quite a bit ☐ A great deal ☐ To an extreme

34. How much you would say you worry about whether your child/children (present or future children) will develop cancer in the future?

☐ Not at all ☐ A little ☐ Quite a bit ☐ A great deal ☐ To an extreme

Discussion with Professionals

35. Have you ever spoken to any of these professionals about cancer and heredity? (Check all that apply)

☐ Internist/Primary Care Doctor

☐ Gynecologist

☐ Oncologist

☐ Other doctor_____

☐ Your child's pediatrician

☐ Genetic counselor/Geneticist

☐ Nurse

☐ Social Worker

☐ Psychotherapist

☐ Others (who?) _____

☐ NONE OF THE ABOVE

36. Have you ever:

Had Cancer Genetic Counseling	☐ Yes	☐ No	☐ Don't know
Had Genetic Testing for cancer gene	☐ Yes	☐ No	☐ Don't know
Gotten cancer genetic test result	☐ Yes	☐ No	☐ Don't know
If tested, test result was	☐ Positive	☐ Negative	☐ Indeterminate

BREAST CANCER GENETICS QUESTIONNAIRE

Please answer all of the questions below. Feel free to say you don't know. Genetic medicine is a new field and many professionals are taking courses to learn about the genetic advances in recent years. So, please do not feel badly if you are not sure of all the answers. But please do try to give one answer for each item.

CIRCLE THE ANSWER YOU BELIEVE IS CORRECT:

	True	False	Don't Know
1.50% of inherited genetic information (about breast cancer risk) is passed down from a person's mother.	True	False	Don't Know
2. 25% of inherited genetic information (about breast cancer risk) is passed down from a person's father.	True	False	Don't Know
3. There is more than one gene that can increase the risk of breast cancer.	True	False	Don't Know
4. A woman who has a sister with a breast cancer gene mutation has a 1 in 4 chance of having a gene mutation herself.	True	False	Don't Know
5. A father can pass down a breast cancer gene mutation to his daughters.	True	False	Don't Know
6. One in 10 women has a breast cancer gene mutation.	True	False	Don't Know
7. All women who have a breast cancer gene mutation will get cancer.	True	False	Don't Know

If the currently available genetic tests were to indicate that a woman has a breast cancer gene mutation, she is at increased risk for:

8. Breast cancer	True	False	Don't Know
9. Ovarian cancer	True	False	Don't Know
10. Lung cancer	True	False	Don't Know
11. Bladder cancer	True	False	Don't Know

If a woman who already had breast cancer was found to have a breast cancer gene mutation, she is at increased risk for developing:

12. Another breast cancer	True	False	Don't Know
13. Ovarian cancer	True	False	Don't Know
14. Lung cancer	True	False	Don't Know
15. Bladder cancer	True	False	Don't Know
16. Women who test positive for breast cancer mutations are generally more likely to develop breast cancer at a young age	True	False	Don't Know

17. A man who carries a breast cancer gene mutation has an increased risk of developing breast cancer himself. True False Don't Know

18. If a woman tests positive for a breast cancer gene mutation, her male relatives' risk for developing prostate cancer are lowered. True False Don't Know

19. A woman may be at greater risk for developing ovarian cancer if she has several close relatives with ovarian cancer. True False Don't Know

20. A woman may be at greater risk for developing ovarian cancer if she has several close relatives with breast cancer. True False Don't Know

21. A woman who has her healthy ovaries removed will definitely not get ovarian cancer. True False Don't Know

22. A woman who has her breasts removed will definitely not get breast cancer. True False Don't Know

23. Screening for ovarian cancer often does not detect a tumor until it is more advanced. True False Don't Know

Directions: Please check one answer for each question #24-27.

24. How many copies of a <u>non-working</u> breast cancer gene must one inherit to be at inherited risk for breast cancer?

a. 0
b. 1
c.3
d. Don't know

25. What is the approximate risk that the average women in the United States will develop breast cancer in her lifetime:

a. 12%
b. 24%
c. 58%
d. 72%
e. Don't know

26. If a genetic test were to indicate that a woman inherited a breast cancer gene mutation, then how likely is she to develop breast cancer in her lifetime?

a. Up to 15% chance
b. Up to 25% chance
c. Up to 40% chance
d. up to 50% chance
e. up to 85% chance
f. Don't know

27. Select the procedure that is NOT appropriate for the detection of ovarian cancer:

a. ultrasound
b. pap smear
c. CA-125 blood test
d. pelvic examination
e. Don't know

Directions:
Indicate how frequently each of these comments was true for you during the past seven days in relation to **inherited predisposition to breast/ovarian cancer.** Please **circle the word that best fits your experience over the past 7 days.**

	Not at all	Rarely	Sometimes	Often
1. I thought about it when I didn't mean to.	Not at all	Rarely	Sometimes	Often
2. I avoided letting myself get upset when I thought about it or was reminded of it.	Not at all	Rarely	Sometimes	Often
3. I tried to remove it from memory.	Not at all	Rarely	Sometimes	Often
4. I had trouble falling asleep or staying asleep because of thoughts about it that came into my mind.	Not at all	Rarely	Sometimes	Often
5. I had waves of strong feeling about it.	Not at all	Rarely	Sometimes	Often
6. I had dreams about it.	Not at all	Rarely	Sometimes	Often
7. I stayed away from reminders of it.	Not at all	Rarely	Sometimes	Often
8. I felt as if it hadn't happened or wasn't real.	Not at all	Rarely	Sometimes	Often
9. I tried not to talk about it.	Not at all	Rarely	Sometimes	Often
10. Pictures about it popped into my head.	Not at all	Rarely	Sometimes	Often
11. Other things kept making me think about it.	Not at all	Rarely	Sometimes	Often
12. I tried not to think about it.	Not at all	Rarely	Sometimes	Often
13. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	Not at all	Rarely	Sometimes	Often
14. Any reminder brought back feelings about it.	Not at all	Rarely	Sometimes	Often
15. My feelings about it were kind of numb.	Not at all	Rarely	Sometimes	Often

THIS PAGE WILL BE SEPARATED FROM THE QUESTIONNAIRE WHEN RECEIVED

Could you please tell us when it would be best for us to try to reach you to schedule our phone interview for this project:

Best times:_____

Best days:_____

Phone numbers: Please give us your phone numbers and tell us if it ok to call that number to reach you

Day:_____ ☐ ok to call

Evening or weekends:_____ ☐ ok to call

Cell:_____ ☐ ok to call

THANK YOU.

PLEASE RETURN TO US <u>WITH ONE SIGNED COPY OF THE CONSENT FORM</u> IN

THE STAMPED ENVELOPE PROVIDED.

Return to: **Dr. Andrea Patenaude**
Dana-Farber Cancer Institute
450 Brookline Ave. D1029
Boston, MA 02115

TELEPHONE INTERVIEW SCHEDULE FOR DEVELOPMENTAL INTERVIEW

PARTICIPANT NUMBER: _____ INTERVIEWER:_____

DATE: _____

START TIME: _____ END TIME: _____

INTERVIEW LENGTH (MINUTES): _____

FIRST, THANK YOU VERY MUCH FOR YOUR WILLINGNESS TO PARTICIPATE IN THIS INTERVIEW.

THE GOAL OF THIS PROJECT IS TO LEARN AS MUCH AS WE CAN ABOUT HOW YOUNG WOMEN WHOSE FAMILIES HAVE BEEN AFFECTED BY CANCER OR THE RISK OF CANCER THINK ABOUT RISKS FOR THEMSELVES AND OTHERS AND HOW THEY THINK ABOUT THEIR OWN HEALTH. WE ARE HOPING THAT YOU CAN HELP US TO PLAN HOW TO TALK TO OTHER YOUNG PEOPLE YOUR AGE ABOUT THESE THINGS.

WE ARE VERY INTERESTED IN YOUR THOUGHTS AND OPINIONS, SO PLEASE TAKE AS LONG AS YOU LIKE TO ANSWER OUR QUESTIONS.

I WOULD LIKE TO SAY AGAIN THAT YOU ARE FREE NOT TO ANSWER ANY QUESTION YOU DON'T WANT TO ANSWER AND YOU CAN ALSO STOP THE INTERVIEW AT ANY TIME. ALSO, FEEL FREE TO SAY I DON'T KNOW AT ANY POINT. WE DO NOT EXPECT THAT YOU WILL KNOW THE ANSWERS TO ALL THE QUESTIONS WE ASK.

BEFORE WE BEGIN, ARE THERE ANY QUESTIONS YOU WOULD LIKE TO ASK ME?

GENERAL INFORMATION- CURRENT STATUS

1. First, Can you please start by telling me a bit about yourself, about your life currently – where are you in school or work, what do you think about for your future, what's most important to you now?

2. How do you think about your own health now?

3. Do you think at all about insurance – health, life, disability? If so, what do you think?, do?

4. Do you do anything in particular to try to stay healthy? If yes, What do you do?

CANCER

1. Would you say that cancer runs in your family?

2. How you would say cancer or the risk of getting cancer has affected your family?

3. How much do you worry about getting cancer yourself?

   What triggers your worries?

   What is your specific worry, if any?

   Do you tell anyone about that worry?

4. How much do you worry about other people in your family getting cancer (or getting cancer again?) Who do you worry about?

5. Who in your family has had genetic testing for cancer genes?

Relationship	gene tested	when done	result	Subject's reaction

FINDING OUT

1. How did you find out that your mother (or other relatives) had been tested?

   Probes, if not clear:
   Did you go with your mother when she was tested?

   When she got her result?

   Whenever daughter was informed:
   What exactly were you told?

   How old were you?

   Do you know what gene she was tested for? And what was found?

   How long after your mother knew the result?

   Who was present when you were told? Who spoke?

   Do you remember what went through your head as you were being informed?

   How did you react immediately?

   Later?

   When has it come up subsequently? How often? What brings it up?

2. Did the person informing you have any particular message they were trying to get across about the meaning of this information either for themselves or for you? If yes, what message? How did you feel about that message?

3. How do you now think about the meaning or importance of this information to you?
   Probe: Did this information change how you think about cancer and your family?
   (Clarify if not clear, if daughter herself has been tested and, if so, how that changed meaning or importance of the genetic information for her)

4. What type or types of cancer does this information relate to for you or for other members of your family?

5. Did having this information (either mother's result or, if tested herself, mother's and her result), change any of your thinking about your future, either what you might want to do or the timing of what you plan to do?

TALKING WITH OTHERS

1. Were you given any guidelines about people to talk to or not talk to about it?

   Whom have you talked with about this information? How have these discussions gone?

   Probes:

   a. Mother

   b. Father

   c. Sisters

   d. Brothers

   e. Other relatives

   f. Friends

   g. Significant Other

2. Have you talked to any medical professionals about inherited cancer risk?

   If no: has it just not come up or did you choose not to speak about it?

   If yes: who did you talk to , how did it come up , about what, how did you feel about those conversations?

3. Have you spoken to anyone else who is in a position similar to yours, i.e. having a tested relative? How was that for you? Would it be helpful?

4. Was there anyone you wanted to speak to about this who you haven't been able to talk to?

   If yes: whom? why wasn't it possible?

5. Have there been times when you wanted to hear **less** about genetics or genetic testing or related matters, when you wished people didn't talk about it to you so much?

   If yes: could you tell us about those times?

6. Are there things you wish you knew or understood better about this area?

   Things you wish you didn't know or feel you would have been better off not knowing?

7. Based on your own experience, what do you think is the ideal age or time for parents to talk to their children about their own hereditary cancer risk or test results?

THINKING ABOUT COUNSELING AND TESTING

1. How old were you when you learned that there was testing YOU could have at some point in your life which could tell you about your own hereditary cancer risks?

   How did you feel about testing then?

   How now?

   How much do you think about testing?

2. Have your parents given you advice about getting tested, either whether to have it or when to have it?

   Has anyone else talked to you about genetic testing for yourself?

3. Have you ever spoken to a genetic counselor?

   If yes: how did that come about? Who went? How was it for you? What did you learn?

   If no,: did you ever want to? Would you know how to find a genetic counselor?

4. Have you ever seen any ads on TV or in magazines about testing for hereditary cancer genes?

   If yes: what effect, if any, did the ads have on you?

5. **If clear subject has been tested, skip to Q. 7.** What do you think now about getting tested?

   Do you have a clear idea of what you want to do? If so, what?

   What are the pros and cons?

   Thoughts about testing later on in life? Never?

   Need more info to decide? Where would you get that info?

6. If she decides she wants to be tested, is there an age or a time in a woman's life when it would be ideal for her to get testing?

7. **If not tested, skip to Q. 9b.** How did your testing come about? How did it feel to wait for results? Have you gotten results? What was your reaction to results?

   If got results: how did you feel about your result?

   If not gotten results: do you have a plan for getting them or just not now?

8. Whom have you told about your test result? Family? Friends? Doctors?

9. a. Is there an age or a time in a woman's life when it would be ideal for her to get testing?

   b. **(SKIP TO HERE)** What do you think should be the youngest age at which people with hereditary cancer risk in their family should be able to be tested to see if they carry that increased risk (minimal age)? Why?

10. Do you think there should be genetic counseling for kids before the age when they can usually be tested to answer questions about genetic risk?

    If yes: how should it work?

HEALTH BEHAVIORS

1. When do you go to a doctor?
   Probes:
   How often?

   what type?

   Do you feel like your doctor really knows you?

   Do your doctors know about hereditary risk in your family? your result **(if appropriate)**?

2. Has anyone talked to you about things that you can do to try to prevent cancer either now or in the future?

   If no: skip to Q. 3.

   If yes:
   Who?

   What?

   When?

   How did you feel when these things were brought to your attention? (**Probe:** Hopeful, Avoidant or Other feelings)

   How often do you think about these things?

   How do you feel when you think about those things now?

3. **(SKIP TO HERE)** Do you do anything to try to prevent cancer that is related to knowledge of hereditary cancer risk?

4. At what age do you think you will start having mammograms?

   How often would you plan to have them then?

   How would you arrange to have a mammogram?

   How do you think they will get paid for?

5. Is there anything else you know of that a woman who might be at hereditary risk for cancer might do to reduce her risk of cancer?

6. Are there/were there things that your mother or other relatives have done/did to try to prevent cancer?

   Do you know other people who are doing special screening or other things because of having hereditary cancer risk?

   How did you feel about their doing those things?

   Does their experience influence your thoughts about what you might do?

7. Have you ever heard of any of the following? **If yes, what have you heard about them?**

   Breast MRIs

   Clinical breast exams

   Breast self-examination

   Prophylactic or risk-reducing mastectomy

   Prophylactic or risk-reducing oophorectomy

   CA-125 test

   Transvaginal ultrasound

HEREDITY IN THE NEWS

1. Where do you get most of your information about hereditary cancer or genetic testing?

2. How often do you come upon an article or program about cancer and genetics? Do you typically read it or listen or not? How do you find the level of the information?

FUTURE RESOURCES

1. How much do young people who are from families with increased hereditary cancer risks want to know about the risk and their options? When and how should it be discussed?

2. Would it be helpful if there were an information source geared specifically to young people who might have such hereditary risk?

   If not: why not?

   If so: what format would be best (written brochure, video, Internet website, other)?

   What should it include?

   Not include?

   Who should deliver the message?

   Can you imagine a situation where you might use this information source?

RESPONSE TO PARTICIPATION Subject Feedback Section

Thank you for taking the time to participate in this interview. Now I would just like to ask you a few more questions about how it was for you to participate in this interview.

1. How have you felt answering these questions today?

2. Did you feel distressed in any way by any aspect of participating in this study?

   If yes- Can you tell me a bit about what caused you distress? How distressing was it?

3. Did you find participating in this interview helpful in any way?

   If yes- In what way(s)

4. Were there any questions you didn't like or that we could have asked in a better way?

   If yes- Which questions?

5. Are there important questions for cancer survivors related to cancer and heredity which we have left out?

6. Is there anything that you would like to know more about that we talked about or touched on today?

Thank you. (Turn off tape recorder).

Confirm address as to where the honoraria should be sent.

END TIME: _____

SAMPLE PAGES FOR PILOT INTERVENTION (TEXT)

HOME PAGE

Main banner: Do you have a parent who carries a BRCA mutation?

Program name: 25: Staying Alive and Healthy

Subtitle: A space where young women can learn about inherited cancer risk

- Current information from experts
- What you can do to stay well
- Experiences of other young women

Main navigation

Cancer in my family

My risks

Staying healthy

Feelings about it all

Talking to others

My plan for me

Personalization options

I'd like to get:

- Guidance from a genetic counselor
- Information from a physician
- Stories about their experiences from other young women

Social media icons
Find us on Facebook
Follow us on Twitter

Institutional branding
Dana-Farber Cancer Institute (with logo)
Funded by: Congressionally Directed Medical Research Program –Breast Cancer Research Program Idea Grant BC084061;
Developed by DF/HCC Health Communication Core

GENETIC COUNSELING LANDING PAGE

(Image of a lovely and kind woman]
Genetic counselors are health care professionals trained to help people learn about how cancer has affected their families and what their own risk might be. For example, a genetic counselor can:

- Give you information about how *BRCA1* or *BRCA2* genes are inherited and what the risks are to those in the family who carry a mutation
- Help you find out if you carry a mutation
- Offer guidance for those who are carriers about options for early screening and prevention options you may want to consider
- Advise non-carriers about their risks.
- Help you to organize what you need to do first –especially, if you are a carrier, that by age 25 you would be advised by experts to begin screening

  Listen to a question-and-answer session with a genetics counselor

.
Here are some topics that young women frequently ask me about. You can read them all to see the "big picture" or just read the sections that feel most useful to you today. Click on the **topic** (link to list of topics) you're interested in or look at some of the additional features (link to list of features).

What would you like to know more about?

Cancer genes: What are *BRCA1* and *BRCA2* genes? What does gene "mutation" mean?
You can also hear a doctor explain these genes
Watch a video about cancer genes and how they work

Cancer risk: What cancers are mutation carriers at higher risk for?
You can also listen to a genetic counselor talk about cancer risk
Link to lots of useful resources

Genetic counseling: What's a genetic counseling session like? How can it help me learn more about the cancer in my family and my own risks.
You can also find a cancer genetic counselor
Send a question to a genetic counselor

Family history: What do I need to know about cancer in my family in order to understand about my personal risks?
You can also fill out an online family history questionnaire

Genetic testing: What is it? What will it tell me? Where is it done?
You can also listen to a genetic counselor discuss genetic testing
Watch a slideshow that takes you through the genetic testing process
Read journal entries from young women before, during, and after genetic testing

Staying healthy: Different ways of **screening for cancer** that experts recommend for women with genetic risk.
You can also listen to other young women talk about their screening decisions

My feelings about the cancer in my family: What are all these feelings? Who can help me sort them out?
You can also listen to young women talk about their feelings and experiences
Talk to a psychologist

My timeline--what steps might be important for me to take and when are the best times for making the right decisions for myself..
You can also look at a timeline of options and recommendations
Make a personal plan

DATING: WHAT DO I SAY, WHEN DO I SAY IT?

(This section will appear after the person has read about talking with friends and others about issues related to hereditary cancer.)

(Image of a lovely and kind young woman]
Many of us wonder about when to talk to our boyfriend or girlfriend about the hereditary cancer in our family. What do I say? When do I say it? Will it affect our relationship? Will he or she start worrying about me? Will it scare him or her away?

Most people discover that their relationship is not harmed by talking openly with their partner about hereditary cancer risk. If the relationship is a strong one, the partner is concerned most of all about the safety and health of the person he or she loves. They want to help her do what she can to stay healthy. Both people also may find it helpful to share their worries and hopes about the future with each other!

Here's what other young women had to say:

- "I talk about it when the topic comes up naturally. As we started getting to know each other, I talked about my mom and her cancer and how that has affected me. That led to talking about the fact that the cancer is hereditary and, at some point, to talking about what I think my own risks are." Amanda G.
- "It used to be hard to talk because I wasn't really sure what I was talking about or how I felt about it. I feel much more comfortable about myself now, and much more comfortable with the information. So talking about it is not the big scary deal it used to be." Melissa N.
- "I know it's the right time is when I feel comfortable enough with the other person." Donna S.
- "I like to wait a while to see how the relationship is developing to talk about it." Shirronda A.
- "Don't try to force it as a test of the relationship. This could be misinterpreted in ways that prove hurtful." Jane T.
- "I find it made our relationship closer, because we were talking about issues that affect our lives together." Sheila W.
- Listen to other young women's stories...

TELEPHONE INTERVIEW SCHEDULE FOR PILOT INTERVENTION

Discussion guide
BRCA prototype

Hi and thanks for speaking with us. My name is _____ I'm from the Dana-Farber Cancer Institute in Boston. We're conducting phone interviews with (_____) to get their feedback on the prototype of an online resource we're developing for young women at hereditary risk of cancer.

Participation in this interview is completely voluntary. You can choose to not answer questions, or to end the interview at any time.

With your permission we will be tape recording this session. We are doing this because we want to make sure that we remember everything that you say. Your comments are really important to us. Everything that you say is confidential and will not be shared with anyone other than the research staff. I want to encourage you to speak openly about your ideas. This is not a test - there are no right or wrong answers. You won't hurt my feelings if you tell me you don't like something or if you have an idea about what might work better. Your opinions and experiences are valuable to us, and we really want to hear what you think. Your feedback will help us improve the resource we are developing for other young women.

Can we start the interview now?

Do you have a computer with internet access in front of you?

Please open the email message you see from us and click on the link in the email.

This is a sketch of what the home page of this website might look like. The actual website would be more fully developed. This sketch is intended to give you an idea of what might be included. Please take a minute to look it over.

What is the first thing you noticed on the home page? What did you notice next?

What does this home page tell you about who the site is for and what visitors will find there?

What is your first response to the home page? (Likes? dislikes?)

How does looking at it make you feel?

Does the home page make you feel like this is a website for someone like you--someone your age, with your interests?

What is your response to the main banner, “Do you have a parent who carries a *BRCA1* or *BRCA2* mutation?” Does it get your attention? Turn you off? Draw you in? Should it say something else? Do you have any suggestions?

What do you think about the name of the program: “25: Staying Alive and Healthy”?

What do you think about the description of the website, “A space where young women can learn and talk about inherited cancer risk.” Is it clear? Does it make you feel that this is a good place for you to find information? Find support? If it doesn’t work for you, does a good description come to mind?

Please take a look at the topics on the left-hand navigation buttons.

What would you expect to see in the “Cancer in my family” section?

...In the “My risks” section?

...In the “Staying healthy” section?

...In the “Feelings about it all” section?

...In the “Talking to others” section?

...In the “My plan for me” section?

Do you think the information here would be useful for you?

Should any of these buttons be worded differently?

Is there something additional you would like to see here?

Please look at the right-hand column where you can select different kinds of information from different sources, like a physician or a peer or a genetic counselor. Would you find it useful?

Please look at the social media buttons in the upper right-hand column. Would you link to any of these? Are any missing? How do you think we could use social networking to reach out to other daughters?

Please look at the bottom of the page where Dana-Farber Cancer Institute, the site’s funder, and the site’s developer are identified. Is this information useful? How does it make you feel?

Overall, what do you think about the colors of the home page? (like, dislike, what would be better?)

What do you think about the layout of the home page? (like, dislike, what would be better?)

Overall, does this site look like the information is trustworthy? Yes/why? No/why not? No/what would make it look more trustworthy)

Overall, does this site look appropriate for the topic, which is hereditary cancer risk, and its main audience, which is young women 18-24? Yes/why? No/why not? No/what would make it look more appropriate)

OK, thanks, that's great. I really appreciate your feedback. There are two other pages that I'd like you to take a look at. Please scroll down to the next screen (Genetic Counseling)

What is the first thing you noticed on this page?

What did you notice next?

This page is the introduction to a section of the site on genetic counseling. Please take a minute to read the page. Nothing on the page is clickable but we've underlined words that could link to other pages or to interactive features like an online tool or a video.

Ok now I'd like to ask you some questions about this page.

What's your response to the image of the woman who is a genetic counselor?

Is her explanation of genetic counselor services clear? Helpful? How does it make you feel?

Would you want to listen to a question-and-answer session with a genetics counselor?

Now let's look at the information below "What would you like to know more about."

Would you be able to find the information you're looking for in this list of topics?

Would you want to:

...Hear a doctor explain *BRCA1* and *BRCA2* genes?

...Watch a video about cancer genes and how they work?

...Listen to a genetic counselor talk about cancer risk?

...Link to resources? What kind of resources would you like there to be here?

...Find a cancer genetic counselor?

...Send a question to a genetic counselor?

.....Fill out an online family history questionnaire?

...Listen to a genetic counselor discuss genetic testing?

...Watch a slideshow that takes you through the genetic testing process

...Read journal entries from young women before, during, and after genetic testing?

...Listen to other young women talk about their screening decisions?

...Listen to other young women talk about their feelings and experiences?

...Talk to a psychologist

...Look at a time line of recommended screening and prevention options?

...Make a personal plan?

Any other thoughts about this page?

Is there too much content, too little, the right amount?

Is the organization confusing or clear?

Did you find it easy to read or hard to understand?

Did the information sound trustworthy and reliable?

How did the information make you feel? Interested, afraid, confused, curious...?

Is there anything here that should be removed?

Ok this is really excellent. There is just one more short page that I'd like your feedback on Your comments are very helpful and I appreciate your willingness to help us out with by sharing your thoughts.

Please scroll down one more page, to the page titled Dating.

What's your response to the image of the young woman? Is she someone you would relate to? Trust?

What's your response to her description of her thoughts about dating and talking about her family's history of cancer? Is it clear? Confusing?

Did you find the quotes from other young women helpful?:

Would you want to listen to other young women's stories?

Excellent, thank you so much. I have a few final questions.

Please scroll down to the final page. This is not part of the website. It shows a few different ways of approaching the graphics on the site. We're not proposing to use these, in fact we've borrowed them from other materials. But we'd like to know if any of them appeals to you.

Now you don't need to look at anything on your computer. Here are some ideas we had of features that could be on the site, we'd like to know if you would find them useful.

Basic definitions

Peer stories told in journal entries.

...Told in audio.

...Told on video.

Advice from mothers, aunts, and grandmothers

How to find a Genetic Counselor

How to find a Cancer Genetics Doctor

Opportunity to talk with a psychologist on the phone

Resources--like websites, research articles

Information For Friends that would help them help you

Frequently Asked Questions

Discussion of Myths and Misconceptions

Finally,

Anything that you think we have left out that should be in a website like this?

That is the end of our questions. How has it been for you to answer these questions today?

Was there anything distressing or upsetting to you in answering them?

Anything interesting or thought-provoking about answering them?

Concluding thank you....We are very grateful to you for sharing your thoughts with us. We will use them to help us plan next steps in the development of this website. Your opinions and reactions are very helpful to us.

I will just turn off the tape recorder now so I can confirm the address to which we will send your gift card.

TURN OFF TAPE RECORDER.


25: STAYING ALIVE AND HEALTHY
find us on Facebook
follow us on Twitter
A space where young women can learn about inherited cancer risk
Do you have a parent who carries a BRCA mutation?
Learn more. Browse through these links to find out how you can take charge of inherited cancer risk.
Cancer in my family
My risks
Staying healthy
Feelings about it all
Talking to others
My plan for me
I'd like to get:
Guidance from a genetic counselor
Information from a physician
Stories about their experiences from other young women
DANA-FARBER CANCER INSTITUTE
Funded by: Congressionally Directed Medical Research Program—Breast Cancer Research Program Idea Grant BC084061
Developed by DF/HCC Health Communication Core

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find us on Facebook | follow us on Twitter

Cancer in my family | My risks | Staying Healthy | Feelings about it all | Talking to others | My plan for me

Genetic Counseling

GENETIC COUNSELORS are health care professionals trained to help people learn about how cancer has affected their families and what their own risk might be. For example, a genetic counselor can:

- Give you information about how BRCA1 or BRCA2 genes are inherited and what the risks are to those in the family who carry a mutation
- Help you find out if you carry a mutation
- Offer guidance for those who are carriers about options for early screening and prevention options you may want to consider
- Advise non-carriers about their risks.
- Help you to organize what you need to do first–especially, if you are a carrier, that by age 25 you would be advised by experts to begin screening

Here are some topics that young women frequently ask me about. You can read them all to see the "big picture" or just read the sections that feel most useful to you today. Click on the topic (link to list of topics) you're interested in or look at some of the additional features (link to list of features).

What would you like to know more about?

Cancer genes: What are BRCA1 and BRCA2 genes? What does gene "mutation" mean?

Cancer risk: What cancers are mutation carriers at higher risk for?

Genetic counseling: What's a genetic counseling session like? How can it help me learn more about the cancer in my family and my own risks.

Family history: What do I need to know about cancer in my family in order to understand about my personal risks?

Genetic testing: What is it? What will it tell me? Where is it done?

Staying healthy: Different ways of screening for cancer that experts recommend for women with genetic risk.

My feelings about the cancer in my family: What are all these feelings? Who can help me sort them out?

My timeline: what steps might be important for me to take and when are the best times for making the right decisions for myself.

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Dating: What do I say, when do I say it?

Many of us wonder about when to talk to our boyfriend or girlfriend about the hereditary cancer in our family. What do I say? When do I say it? Will it affect our relationship? Will he or she start worrying about me? Will it scare him or her away?

Most people discover that their relationship is not harmed by talking openly with their partner about hereditary cancer risk. If the relationship is a strong one, the partner is concerned most of all about the safety and health of the person he or she loves. They want to help her do what she can to stay healthy. Both people also may find it helpful to share their worries and hopes about the future with each other!

Here's what other young women had to say:

"I talk about it when the topic comes up naturally. As we started getting to know each other, I talked about my mom and her cancer and how that has affected me. That led to talking about the fact that the cancer is hereditary and, at some point, to talking about what I think my own risks are." Amanda G.

"It used to be hard to talk because I wasn't really sure what I was talking about or how I felt about it. I feel much more comfortable about myself now, and much more comfortable with the information. So talking about it is not the big scary deal it used to be." Melissa N.

"I know it's the right time is when I feel comfortable enough with the other person." Donna S.

"I like to wait a while to see how the relationship is developing to talk about it." Shirronda A.

"Don't try to force it as a test of the relationship. This could be misinterpreted in ways that prove hurtful." Jane T.

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